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TITLE PAGE

Older people's perspectives on dignity: the benefits and challenges of a qualitative longitudinal approach to researching experiences of later life

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Abstract

This article discusses findings from a qualitative longitudinal study of dignity in later life, which focused on the perspectives of older people at a time when their need for help and support was increasing as a result of long-term illness. It reflects critically on the methodology for its ability to generate knowledge about this eventful and unstable period of the life-course. It is argued that a longitudinal qualitative approach provides the optimum conditions for researching older people's perspectives on their health and illness as well as on their experiences of being helped and supported. It sheds light on the changes they faced in their relationships, their home environments and their daily lives as well as how they dealt with these changes while maintaining their dignity.

Introduction

This article presents a discussion of a qualitative longitudinal (QL) study of dignity in later life and reflects critically on the methodology. The study, which was part of the UK New Dynamics of Ageing Programme, took place between November 2007 and June 2012, with 31 months of field work in the cities of Bristol and Nottingham. Thirty four older participants took part, all of whom had long-term serious health problems that had given rise to varying degrees of need for help and support in daily life. The research questions addressed were:

1. What accounts are given about dignity in daily life by older adults?
2. What resources are available to them to draw upon?
3. What factors are perceived to support or undermine a sense of dignity?
4. What preparations do older adults who are facing death at a near but uncertain time make for the process of death and dying?

Rationale for the research design

In the UK, increased life expectancy has typically meant added years spent with complex long-term ill-health, which is often associated with loss of mobility and sensory abilities (Office for National Statistics 2012). The risks are not equally shared. Inequalities in health, illness and life expectancy, related to gender, socio-economic background and other factors, are well established (Nazroo 2015) and are reflected in differences between chronological and physiological ageing. Increasing demand for health and social care services, associated with societal ageing, has

1 generated tensions between the need to contain the *cost* of services and the
2 imperative to promote *dignity* in services. Missing from public debates, however, are
3 the voices of people on the receiving end of support, whose lives have changed
4 profoundly as a consequence of long-term illness.

5
6 This project adds to a growing body of research that seeks to place older people's
7 voices centre stage (Buse and Twigg, 2015). There are moral and epistemological
8 reasons for doing so: Grenier (2012, 2006), for example, points to the continuing
9 dominance of medical discourses concerning 'frailty', which contrast with those of
10 older people whose view of frailty is more fluid. Baxter and Glendinning (2013)
11 highlight the complexity of older people's perspectives on choice-making, which is
12 poorly understood by service providers, while Bornat and Bytheway (2010)
13 demonstrate how older people's views of risk in everyday life challenge normal social
14 work practices. Questioning dominant discourses about old age is an important task
15 for researchers, therefore, not only as a matter of social justice but also to develop
16 knowledge of old age that is grounded in experience and challenges institutional
17 assumptions and dominant cultural discourses.

18
19 Millar (2007) highlights the potential of QL research to examine the subjective
20 experience of personal change, which in our project involved change in participants'
21 health, which had already begun prior to the study and would continue throughout its
22 duration. Of particular interest was how changing health affected participants' day-to-
23 day lives, living arrangements, social relationships, and perspectives on the future –
24 all of which had implications for their dignity. A QL approach was chosen because it
25 would put us in contact with participants over a defined period within this significant

1 time of uncertainty and would enable us to explore their perspectives on the present
2 and future in the context of their earlier lifecourse.

3
4 The concept of the lifecourse emphasises the importance of time, change and
5 continuity within individual lives *as well as* the interrelationship of individual
6 experience and social contexts (Dannefer and Stettersten 2010, Hareven and
7 Adams 1982). It highlights the ways in which particular historical periods and
8 locations shape the experiences of age cohorts as well as differences and
9 inequalities between individuals within these. From the perspective of stage-based,
10 lifecourse research, our participants might be regarded as having made or in the
11 process of making a transition to 'fourth age' – the period of life prior to death in old
12 age that is defined by declining health and increasing dependency. Grenier (2012),
13 however, argues that evidence from older people's accounts shows a variety of
14 individual pathways and thresholds that challenge defined stages. Moreover, as the
15 lifecourse is shaped and influenced by the social and cultural contexts in which we
16 live, it follows logically that there is no standard, measurable threshold between third
17 and fourth ages. In addition, the long-term illnesses that are characteristic of
18 contemporary old age can also mean it is difficult to discern whether an individual is
19 living or dying because of the lengthy and 'dwindling' process they experience
20 (Nicholson et al 2012). Thus, the contours of the fourth age are blurred and
21 differentiated. A QL approach enables the researcher to maintain a focus on
22 individual and social levels and, as Neale and Flowerdew (2003) argue, gives a
23 sense of the dynamic nature of life and the interplay of temporal and cultural
24 dimensions.

1 How long a longitudinal study lasts is an important question (Corden and Millar 2007,
2 McLeod 2003). Saldana (2003) argues that in deciding the 'right' length, each study
3 must take into account its aims and context. In this study the maximum period of
4 participant involvement was 2 years and 7 months. In deciding the length, we had to
5 consider the demands of a longitudinal study and their potential effect on people
6 poor health as well as the possibility that fewer would have signed up to a lengthier
7 study. We calculated that within 30 months there would be sufficient points of contact
8 with appropriate intervals between these to enable us to capture the data we wanted
9 without overburdening the participants.

11 *Methodological and ethical questions*

13 A number of inter-related methodological and ethical questions arose in the process
14 of designing the project. A key point made by Neale (2013), relates to time itself.
15 Apart from the time participants gave to the project, the interview questions were
16 strongly time-related, focusing on participants' earlier lives, recent past and present
17 circumstances as well as the future, which, given their health problems, might look
18 bleak. We considered that participants might be embarrassed about describing their
19 health problems or distressed when talking about death and bereavement. An
20 advantage of QL research, however, is the enhanced potential for trust in
21 researcher-participant relationships, which facilitates discussion of sensitive topics,
22 enabling researchers to judge the optimum moment to raise them. McLeod (2003)
23 argues that openness and fluidity in QL research enables researchers to avoid lines
24 of questioning that might appear confrontational in a one-off interview. Based on our
25 prior collective experience we expected participants to change their views about, for

1 example, where they wanted to live or how they wanted to be supported. We framed
2 our questions accordingly: 'How do you feel about X now?' and 'Since we last met
3 have you thought any more about Y?'

4
5 Longitudinal research is demanding of participants' time and energies and rewards
6 are appropriate (Neale 2013). Our intention to give participants gift tokens was
7 disallowed by the NHS Local Research Ethics Committee but we sent Christmas
8 cards and telephoned between interviews to enquire about events we knew were
9 coming up, such as moving house. We also had a duty to end the fieldwork
10 appropriately and invited participants to events with refreshments so we could thank
11 them for their participation and present our emerging findings. In the final interview,
12 we asked participants why they had agreed to take part and how, on reflection, they
13 felt about their participation. Most said that they had been stimulated by the desire to
14 'make a contribution' that could have a positive effect in future. All said they had
15 enjoyed being a part of the study and some that they had benefited from the
16 opportunity to reflect and 'unburden' themselves.

17
18 The question of attrition frequently arises in the context of longitudinal qualitative
19 studies (Koro-Ljungberg and Bussing 2013). In this study, we had to consider the
20 possibility that participants' health would be adversely affected by being involved.
21 We were prepared to stop or rearrange interviews if necessary and asked at each
22 encounter if they were happy to continue with the study. We offered participants the
23 option of selecting a supporter for the duration of the study. Supporters acted as a
24 point of contact if a participant was unable or unwilling to contact us direct and as
25 potential interviewees if a participant was too unwell to be interviewed. All but five

1 chose a supporter, mostly their spouse or partner, but also sons, daughters and
2 friends. The involvement of supporters is a valuable means of facilitating the
3 inclusion of people in poor health in research projects but the longitudinal approach
4 increased the likelihood that their involvement – especially when they were the
5 spouse or partner - became more that of a 'co-participant'. This sometimes required
6 sensitivity in the interviews as well as care to analyse the data separately.

7
8 We were prepared for deaths among the participant group and did not regard these
9 as attrition in the usual sense. On the contrary, we wanted to learn about the ways in
10 which participants were supported through the process of dying and to interview
11 supporters as early as appropriate after the death. Six died during the study but the
12 other 28 remained throughout. We also needed to take account of possible loss of
13 mental capacity and the effect of this on participants' ongoing consent to participate.
14 All participants gave consent in writing at the outset and verbally at the beginning of
15 each subsequent interview when the researcher checked that the participant was
16 clear about the purpose of the study and their participation in it before proceeding.

17
18 After obtaining ethical approval we began recruiting participants through three
19 general practices and two day centres. Response rates were variable: the overall
20 rate from GP recruitment was 20.6% (10%, 22% and 32% across the 3 practices).
21 Calculating response rates from the day centres was difficult, as the invitations were
22 issued openly to people attending at different times. The final group of 34
23 participants all lived in their own homes at the beginning of the study. Four were in
24 supported housing, 15 lived alone and 19 with their partner. One was of South Asian
25 heritage; the others were white British. There were 21 men and 13 women, which

1 was an unusual gender balance for this age group. To explore possible reasons for
2 this we reviewed our recruitment procedures but were unable to identify an
3 explanation.

4 Table 1 shows selected characteristics of the participant group at the time of the first
5 interview.

6
7 *TABLE 1 ABOUT HERE*

8
9 Mindful of the impact of socioeconomic inequalities, we decided on selection criteria
10 that combined age *and* current health status, with age 75 and over as our target age
11 group (we also recruited one 70 year-old). To enable us to include a range of health
12 and illness trajectories, the GPs recruited participants who fell into three groups.

13 Thirteen had had an unscheduled period as a hospital inpatient in the past twelve
14 months (which can indicate a significant adverse health event) *and* high level need
15 for support with, for example, bathing, dressing or eating or requiring frequent visits
16 from a community nurse. Eight participants had similar support needs but no
17 unscheduled inpatient hospital treatment, while the remaining thirteen had needs for
18 ongoing support at a lower level, such as help with shopping and housework.

19
20 *Data collection*

21 Participants were interviewed in their own homes between June 2008 and January
22 2011 by two researchers, each participant being interviewed by the same researcher
23 throughout. Most were interviewed four times, fewer in seven cases because of
24 deaths and serious illness. Nine were interviewed a fifth time because of particular
25 circumstances that we wanted to follow up, such as imminent results of medical

1 tests, or a potential move to a care home. We approached each 'round' with
2 particular topics scheduled but also allowed plenty of time for participants to raise
3 their own. The first round focused on participants' everyday lives, activities,
4 experiences of being supported and their views on ageing and dignity. Data were
5 gathered also on age, marital status, ethnicity, family members, previous
6 employment, tenancy and the length of time they had lived in their home. The
7 second round focused on earlier life (including childhood, work, marriage and
8 relationships) and on participants' personal values and beliefs. The third focused on
9 changes in participants' health and circumstances since the first interview, how they
10 had dealt with these and what support they had. In the fourth round, we reviewed
11 and expanded on topics raised previously and reflected on their participation in the
12 study. If the topic of how they saw the future had not already been raised we
13 covered it at this point, asking about future treatment preferences and whether they
14 had discussed these with their GPs or family members.

15
16 Initial analysis of the transcripts of each round prior to commencing the next
17 highlighted particular points to be followed up. Smith (2003) argues that this practice
18 sharpens the focus of research. In our experience it enhanced the integrity of the
19 research as a process, rather than as a series of one-off encounters and was also
20 beneficial in terms of building relationship of trust. Thus, when a researcher asked;
21 *'Last time I was here, you were waiting to see the specialist about how did that*
22 *go?' participants were encouraged by our interest and attention.*

23
24 The relaxed approach to interviewing did, however, mean that a lot of time was spent
25 listening, sometimes repeatedly, to participants' stories. This time was often

1 enjoyable and contributed to relationship building but it had resource implications,
2 the generation of extraneous data taking up researcher time and increasing the cost
3 of transcriptions. The build-up of relationships was a two-way process that, as Neale
4 (2013) discusses, altered the researcher-participant relationship. Listening to
5 accounts of deaths, bereavements and illness could be distressing for researchers.
6 Hurd-Clarke (2013) notes that researchers are often reluctant to raise questions that
7 might distress older participants, which she suggests might be a form of internalised
8 ageism. On reflection, our need to ask questions related to death and dying in the
9 last round of interviews suggests that we were hesitant to raise them earlier.

11 *Approach to analysis*

12 Face-to face interviews were transcribed verbatim and the transcripts read by the
13 two researchers that had conducted interviews¹. Emergent themes and questions
14 were discussed with members of the research team and an Advisory Group. At the
15 end of the field work there were 134 transcriptions of interviews of between one and
16 two hours as well as notes from telephone calls and field notes. Every transcript was
17 re-read and marked at key points to add to and develop the *a priori* themes and
18 those identified over the course of the study. Our approach to analysis was to
19 produce frameworks with cross-cutting themes on the vertical axis and individual
20 'case' accounts on the horizontal (Lewis 2007). The analytic process was informed
21 by that developed by Spencer, Ritchie and O'Connor (2009) involving progression
22 from descriptive to explanatory themes.

¹The anonymised transcripts are deposited with the Economic and Social Data Service (ESDS).

1 To maintain our focus on the research questions, we initially prioritised cross-cutting
2 descriptive themes, identifying eleven: health and illness; significant relationships;
3 home and environment; everyday life and activities; functional health and mobility;
4 treatment and professional support; independence and obtaining help; ageing; the
5 life-course; the future and preparations for the end of life; dignity. Some themes
6 (including health, medication and mobility) were analysed chronologically, focusing
7 on participants' accounts at the time of each interview and exploring changes
8 through the course of the study. However, as Lewis (2007) found, the significance of
9 the different time points was variable and it was necessary to take a more fluid
10 approach. Individual life stories became increasingly important to the thematic
11 analysis. For example, the theme of 'independence' included everyday things
12 participants did now without help, what they needed help with, from whom, how this
13 had come about and how they felt about independence in general. Below is an
14 extract from a single cell in the framework on independence from interviews with
15 Rose, who lived in supported housing where a warden was employed.

16
17 IV3: [line] 437 '*I think a lot is left to yourself*' [Warden says]: '*I wish they*
18 *were all like you*'. Regrets loss of GP/Nurse home visits. '*You never see*
19 *anybody now*'. Cost of taxi to surgery. The more independent you try to be,
20 the less help you get offered (IV4:1131). But couldn't change her ways
21 '*Brought up that way*' (IV4:1150 - leopard/spots).

22
23 Rose's personal values are inextricably linked with how she was brought up but also
24 with the contemporary cultural value of independence, as implied by the warden's
25 comment. Her account also suggests that if support were provided more routinely

her sense of independence would not be compromised. For Rose, it is having to ask that affects her sense of independence. Her account thus reflects the individual, familial, institutional, social and cultural dimensions of independence. It also shows the persistence of continuing themes in later life, even during a period of significant change in circumstances.

Findings

The discussion of findings below highlights the precarious and unstable nature of participants' lives. Frequent and continual changes affected their day-to-day activities, relationships and living arrangements as well as their perceptions of their lives and identities. It focuses on the significance of these changes for individuals and on their relationship with different sources of help and support, which show how dignity and threats to dignity are experienced.

Health maintenance and long-term illness

The long term health trajectory of each participant was rarely smooth, involving periods of crisis and downturn, as well as relief and upturn. Table 2 gives a summary of participants' descriptions of their health and illness over the course of the study.

Table 2 about here

All participants expressed a strong sense of personal responsibility for maintaining health, typical examples being daily walks, crossword puzzles and care over diets.

1 They also described regular routines they had developed, such as monitoring
2 medication and its side effects, as well as regular appointments for check-ups and
3 tests. At the second interview Peter said:

4
5 *I check my blood pressure because the doctor..... says he wants*
6 *to get it down to 130/80, which it's pretty well near that now. The*
7 *medication's working and I also decided to supplement the*
8 *medication. I bought a book on alternative medicine and found that*
9 *soya milk brings blood pressure down and so does pomegranate*
10 *juice.'*

11
12 As Bytheway (2001) and others have found, decisions over medication often
13 occupied a lot of time and emotional energy. Of the 28 participants alive at the end of
14 our study, 15 had refused, changed or stopped prescribed medication and another 5
15 had discussed these possibilities with their doctors. Unpleasant and sometimes
16 embarrassing side-effects, such as sweating, rashes, dizziness, nightmares, sexual
17 impotence and urinary incontinence, influenced their decisions, as did fear of
18 becoming over-dependent on medication. Sometimes a balance had to be struck
19 between the potential future consequences of stopping and the present-day side-
20 effects of taking medication. James commented:

21
22 *'I told [the Parkinson's nurse] that I left the statins off and I said I'd*
23 *sooner drop dead from a heart attack in a week's time than live*
24 *another 10 years and end up like a...with more and more...like a*
25 *cabbage, you know.'*

1
2 In addition, decisions about medication were often morally charged. For some,
3 compliance with medication was the 'right thing', because having asked for the
4 doctor's advice they should take it. For others, being a 'pill-taker' signified moral
5 weakness, and medication was best avoided completely or taken in reduced
6 dosages, although it might be accepted grudgingly as a necessary evil. Health
7 services were highly valued in general, although several participants gave examples
8 of health professionals they disliked and recounted stories of neglect when they were
9 in hospital. Some experienced rude and arrogant treatment by doctors, which they
10 found deeply undermining of their dignity.

11
12 *Precariousness, time and change*

13
14 The changes in health that had occurred prior to or happened during the study were
15 often described by participants as coming 'out of the blue' and having 'hit me for six'
16 - terminology that portrays a sense of shock and devastation. Some described the
17 onset of ill-health as signifying a major life change or transition, which could be old
18 age itself. Describing the time his knee problem stopped him from getting out, Brian
19 remarked: 'That's when I knew old age was upon me and no mistake'. Corden and
20 Millar (2007) discuss the ways in which past and future time impact on the present.
21 This was clearly evident in our participants' accounts, which were peppered with
22 expressions such as '*I used to*'; '*while I can*'; '*still*'; and '*as long as...*'

23
24 '*I wish I could walk better, but never mind, I can still go out*' (Jane)

25 '*Ageing doesn't bother me as long as I can keep going, like.*' (Robert)

1
2 Such expressions denote the unstable and contingent nature of their lives, the
3 constant awareness of how different things were now from how they used to be as
4 well as how precarious their current circumstances were as they faced an uncertain
5 future. At the first interview, like many others, Graham concentrated on the here-and-
6 now, commenting that looking towards the future is '*a particularly unhelpful thing to*
7 *do because you don't know what lies ahead*'. In the third interview, he said: '*The*
8 *medical men said I must expect things to change a lot*' '*I know things will not get*
9 *better it's only a question of how long I go on*'. Although he found the doctors'
10 prognosis distressing, he also described a sense of relief from the constant
11 disappointment that his efforts with exercise had not improved his mobility. At this
12 point, therefore there was a qualitative difference for Graham in the meaning of the
13 'here and now' because of his changed perception of the future.

14
15 The theme of change permeated all participants' accounts but in qualitatively
16 differing ways. Change in health and mobility could signify, for example, loss of
17 social status, loss of a cherished activity or change in a long-standing marital
18 relationship. Change could be sudden or gradual, episodic or ongoing. While it often
19 came out of the blue it could also be the result of decisions and actions to preserve
20 and maintain a way of life as far as possible or to minimise risk. For example, during
21 the study, several participants decided to give up driving. On the positive side,
22 learning new skills, such as using the internet, texting and Skype, enabled
23 participants to maintain their family and social relationships as well as to explore
24 information about their health and medication and follow personal interests.

1 Change - or the possibility of change - in living arrangements was a major
2 consideration for most participants, particularly those who had lived in their homes
3 for many years. Some agonised over decisions about where to live because, as
4 Degnen (2015) points out, their attachment to home and neighbourhood was deeply
5 significant in terms of their histories and creative activities over the years. They often
6 pointed to home improvements and to articles that had a family history or
7 memorialised a lost partner. Some decided that moving house would be too much
8 trouble at their 'time of life' while others found that, once made, a move could be
9 seen positively in retrospect. Brenda, for example, moved to a care home and found
10 relief from the pressure of living in supported housing, as well as from anxiety about
11 being a burden on her daughter.

12
13 Across a range of topics, participants were often eager to explain the rationale
14 behind decisions they made and to explain how, in retrospect, it was the right
15 decision. The process of resolving dilemmas often involved family members, friends
16 or professionals. For example, at the beginning of the study, Lena was pondering
17 whether or not to have a stairlift installed, because her son was anxious she would
18 fall on the stairs. In the second interview she said that the nurse at the falls clinic had
19 similar concerns but Lena was still reluctant. Some years previously, when her late
20 husband was dying, a stairlift had been temporarily installed and Lena dreaded the
21 prospect of a constant reminder of this dreadful time. By the third interview, she had
22 reluctantly agreed to have the stairlift installed, the deciding factor being the potential
23 effect on her son if she were to have a fatal fall, which she had come to accept was
24 highly likely.

1 The family relationships of participants were also subject to change as a result of
2 their illnesses, and increasing levels of dependency. Most told us how they had
3 come to rely on family members to support them in public, such as in restaurants,
4 public toilets and transport, as well as in diverse ways in private. Participants also
5 described how they reciprocated where they could with, for example, financial help,
6 care of young grandchildren and accommodation for older ones. Some talked about
7 the prospect of family events such as weddings as a reason to stay alive. In
8 response to questions about their preparation for the end of life, many said that they
9 trusted their sons or daughters to make 'the right decision' on their behalf and that
10 they had not considered discussing this with their GPs. The importance of family ties
11 was also evident in the accounts of widowed participants, who described how their
12 growing need for support exacerbated the pain of bereavement. A minority of
13 participants had troubled family histories, including long-standing estrangement from
14 sons and daughters, described with bitter regret and fear about the future. During
15 the course of the study, Dorothy left her partner of twenty years and was helped to
16 move by her friends from the day centre into supported housing. She hoped this
17 separation would bring about reconciliation with her children by her first marriage.
18 Jonathan had been estranged from his daughter since his divorce from her mother
19 but in the third interview was overjoyed about their reconciliation. In the fourth
20 interview, he was considering leaving his wife because as he grew physically weaker
21 he felt threatened by her. The highs and lows of family life were therefore a
22 continuing theme but had particular significance because of participants' advanced
23 age and uncertain future.

24
25 *Independence: perseverance and asking for help*

1
2 Unsurprisingly, independence was widely regarded as crucial to dignity but
3 participants' differed in their views about what it meant in practice. It could mean, for
4 example, 'being able to do what you want to do', 'being able to decide for yourself',
5 'not needing help from anyone' or 'being able to stay in your own home'. Views of
6 independence as an abstract idea often differed from how particular situations were
7 viewed. Peter described himself as '*independent to the point of being daft about it*',
8 yet also said that he and his wife should have had more help when he was
9 discharged from hospital. Participants' sometimes explained why particular
10 circumstances allowed an exception to their general rule. David, for example, said
11 he had only been in a wheelchair on two occasions '*for a proper reason*', such as the
12 convenience of his family, because '*I'm not a wheelchair person*'. Such moral
13 justification was clearly important to participants' continuing sense of self and self-
14 respect. Many participants referred to the importance of moral fortitude and
15 determined mental and physical effort in facing up to the impact of their ill-health.
16 The term that several used was '*perseverance*', which encapsulates their active
17 determination to maximise their capacity for self-reliance, drawing on their personal
18 resources to do so. Over the course of the study, however, participants' views of
19 perseverance often altered as they realised they would have to make inevitable
20 adjustments to their changing health and physical abilities.

21
22 Participants gave vivid accounts of the giving and receiving of help, including from
23 paid staff as well as from families and friends. The prospect of personal (bodily) care
24 was dreaded by those who did not yet need it but the experience of it was at least
25 less negative than expected and could be quite positive if they liked the carers (see

1 also Coleman, Ivani-Chalian and Robinson , 2015; Grenier 2012). Some said that
2 keeping up standards of personal hygiene was the most important consideration
3 while others regarded personal care as the means by which they achieve their aim of
4 staying at home. Help from a family member sometimes mitigated the negative
5 effects of reliance on paid carers. Harry's wife described how, although it was the
6 carers' job, she would get him up in the morning before they arrived '*to preserve his*
7 *independence*'.

8
9 Cuts to services, such as podiatry, community nursing, libraries and social clubs
10 reduced participants' sources of support but also created uncertainty about their
11 entitlement and anxiety about how they would be regarded if they asked for help.
12 Valerie said that asking for help made her feel she was '*a pest*', while Norman said '*I*
13 *think sometimes people think "Oh look at that idle bugger," You know, cos I don't*
14 *(laughs) ... I don't go to work or anything like that, and laying in bed till 9 o'clock in*
15 *the morning*'. Their sense of self-respect was therefore inextricably linked to the
16 accessibility and availability of services.

18 **Discussion**

19
20 Small (2007) comments that what matters most about old age is the human being's
21 heightened exposure to contingent harms related to serious ill-health. This study
22 focused on older people's subjective experiences and perceptions of this heightened
23 exposure and considered the lessons for our understanding of dignity. It has
24 underlined the multi-faceted nature of dignity as involving personal identity and self-
25 respect as well as social status (Lloyd et al 2014). Participants' stories of falling, loss

1 of bodily control and mental confusion portrayed vividly the embodied nature of
2 identity as well as the aesthetic aspect of dignity, which can be easily undermined by
3 such experiences. At the same time, participants differed in how they regarded the
4 significance of their experiences and in the reflexive process each went through as
5 they adjusted to change. The diversity of their experiences and views reinforces the
6 importance of subjective perspectives on the lifecourse, and the challenge to
7 standardised, stage-based models (Grenier 2012). Barnes, Taylor and Ward (2013)
8 highlighted older people's ability to accept themselves as they are, rather than being
9 critical of their inability to meet a standardised measure of independence. This is an
10 important point that resonates with our findings but, as discussed, acceptance
11 involved a continuous process, as there was no stability in participants' situation 'as
12 they are'. The weariness that our participants experienced from time to time often
13 arose from the overbearing necessity to manage changing circumstances, with the
14 prospect that tomorrow could well bring a different challenge.

15
16 As in the longitudinal case studies by Coleman, Ivani-Chalian and Robinson (2015)
17 individual participants in our study differed considerably in how they adjusted to
18 changes. Emotion played an important role in participants' decisions about seeking
19 help from service providers, which support the findings of Baxter and Glendinning
20 (2013, 2011). As discussed, decisions about seeking help were also morally
21 charged and it was important for their sense of dignity and self-respect that they felt
22 they were doing the best they could in the circumstances. We concur with the point
23 made by Millar (2007:538) that a QL approach is uniquely suited to understanding
24 how people explain the relationship between their individual choices and actions and
25 the conditions under which they make these. It was striking how much mental and

1 emotional labour was spent by our participants on making decisions and
2 adjustments, each of which was deeply significant to maintaining their sense of self
3 and their dignity (Lloyd et al 2014). Their perseverance can be understood as a
4 continuous reflexive process of exerting mind over matter while also accepting that
5 matter would, in the end, trump mind.

6
7 This reflexive process occurred within familial, social and cultural contexts as well as
8 by reference to earlier life-course experiences. The findings, thus, also draw
9 attention to the importance of relationships to dignity. As discussed, families and
10 friends were crucially important to enabling participants to deal with their precarious
11 circumstances and losses, to overcome their fears and maintain a sense of security
12 and belonging. Participants often needed help to find a resolution to the ongoing
13 dilemmas they faced, including those related to their living arrangements, and often it
14 was a family member that provided this. The QL method enabled us to trace not only
15 the flux and change of family life during the study but also the ways in which family
16 histories shaped present-day patterns of help and support and influenced decisions.
17 As Degnen (2015) found, this included those who were absent, also. Widowed
18 participants still considered their late partner's views when making decisions.

19
20 Laceulle and Baars (2014) argue that dominant cultural narratives about ageing as a
21 chronological and biological process have come to shape individual expectations as
22 well as obscuring ageing's socially constituted nature. This point is well illustrated by
23 the discussion of participants' unstable views of independence. Within their lifetime,
24 there has been a significant cultural shift as post-war values of shared responsibility
25 for welfare have declined as individualistic values of personal responsibility have

1 been ascendant. Our participants were vulnerable, therefore, not only because of
2 their health problems but also because of their social position as older people in
3 need of help. Jolanki (2009:271) argues that older people 'struggle within available
4 discourses of justification in order to retain their human standing'. In our study, the
5 longitudinal approach has provided insight into the nature of this struggle as
6 participants came to terms with their increasing need in the context of diminishing
7 sources of public help and diminished entitlement as citizens. It has also shed light
8 on the potential of both formal services and family help to maintain older people's
9 dignity when help was offered without participants having to ask for it.

11 **Conclusion**

13 This article has discussed the value of a QL methodology in research into dignity in
14 later life in the context of serious ill-health. It has placed strong emphasis on
15 understanding older people's perspectives on this turbulent time. The findings
16 highlight the scale of changes they experienced and the efforts they made to
17 persevere. They challenge the commonly held but simplistic idea that the dignity of
18 older people in poor health is in the hands of those who provide support and care
19 services. The complex and fluid nature of dignity is underlined by the longitudinal
20 approach. The QL methodology ideally suited to exploring the complex relationship
21 between continuity and change in later life and to drawing out the links between the
22 individual and the familial, cultural and social contexts that shape the conditions in
23 which people age.

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17

Table 1 Selected participant characteristics at Interview 1

Pseudo-nym	Sex	Age	Marital status	Previous occupation	Health (own description)
Henry	M	90	M	Firefighter	Skin cancer,
George	M	87	M	Firefighter	Bowel cancer
Edward	M	85	M	Upholsterer	Falls, fractured ribs, blood clot, irregular heartbeat, gout
Adrian	M	81	M	HGV driver	Non-Hodgkins lymphoma
Jonathan	M	85	M	Own business franchise	Heart triple bypass, knee injury, allergy to 1 medication
Lena	F	80	W	Comptometer, wages clerk	Emphysema, arthritis, lost use of arm, leg ulcer, sleep problems
Andrew	M	80	D	Company director	Cancer, arthritis, hip replacement (awaiting second)
James	M	82	S	Coachbuilder, factory worker	Parkinson's, diverticulitis, IBS, colostomy, allergy to 1 medication
Alice	F	80	D	Secretarial, PA, sales coordinator	Mastectomy (breast cancer), low energy
David	M	84	M	Teacher	Diabetes, leg cramps, chest pains, triple bypass surgery.
Brenda	F	83	W	Factory worker	Diabetes, osteoporosis, angina, triple bypass, hip replaced. Registered blind
Graham	M	78	M	Lawyer	Stroke
Jane	F	75	M	International conference administrator	Sodium deficiency, irregular heartbeat, asthma, broken ankle
Michael	M	84	M	Careers advisor	Ankylosing spondylitis, fall, pneumonia, eye problems
Brian	M	89	S	Army office, writer	Painful knee, accidental injuries
Rose	F	84	W	School clerical, shop assistant	Stroke, diabetes, problems with feet
Margaret	F	82	M	Manager dry-cleaning chain	Stroke
Peter	M	78	M	Mechanical engineer for council	Cancer of the colon, mini-stroke, polymyositis
Stephen	M	83	W	Army, park ranger, geological surveyor	Stroke, cataracts, hernia

Samuel	M	82	M	Own business	Skin cancer, detached retina
Frederick	M	81	CP	Company rep	Heart problems, diabetes, arthritis
Doreen	F	80	M	Factory machinist	Lymphoma, cancer of womb and bowel, cataracts, vertigo, diabetes
Robert	M	83	M	Painter and decorator, factory worker	Arthritis, knee replacement, broken wrist, hoarseness under investigation
Daniel	M	83	M	Post office telecom line manager	Arthritis, funny turns – fainting, ECG.
Norman	M	88	W	Miner	Emphysema, high blood pressure, deafness, 2 knee replacements,
Harry	M	90	M	Business manager (drapery)	Heart failure, angina, colostomy, deafness, cataracts, carpal tunnel, gall-bladder removed
Howard	M	83	W	Photographer, insurance agent.	Aortic aneurism, macular degeneration, hernia, painful feet
May	F	87	W	Lace market, laundry, office and factory worker	Arthritis, low sodium, painful legs
Phillip	M	88	M	Civil servant	Abdominal pain, cataracts removed
Ruth	F	88	W	Catering, post office TV licences.	Parkinson's, cramps, thyroid problem, knee replacement
Dorothy	F	75	M	Hospital drugs dispenser	Osteoporosis, psoriasis, DVT, aortic aneurisms (2), lichen planus
Valerie	F	70	D	Factory worker, care worker	Severe anxiety, depression, asthma
Elizabeth	F	70	W	Shop worker	Tumour behind eye, arthritis, high BP, high cholesterol.
Irene	F	88	W	Factory, shop, office work	Fall, poor eyesight, osteoporosis, painful shoulders

M = married, W = widowed, D = divorced, CP = civil partnership

Table 2: Changes experienced over the course of the study

Given name	Health/illness and significant changes (drawn from participants' accounts)
Henry	Overall slowing down
George	Died before second interview
Edward	Increased mobility problems, prostate cancer diagnosis, jaundice, stent inserted, 2 falls
Adrian	Broken shoulder now healing. Lymphoma in remission
Jonathan	Increasing mobility problems, depression, extreme tiredness
Lena	Deteriorating mobility and use of arm but attended falls clinic and feels more stable
Andrew	Increased pain, high blood pressure prevents surgery, endoscopy for gut problem.
James	Deteriorating Parkinson's, Baker's cyst, deteriorating eyesight, heart problems
Alice	Broken arm but recovered. Loss of energy
David	Becoming weaker and weaker. Several falls
Brenda	Hospitalised for heart attack. Moved to nursing home
Graham	Began using wheelchair, problems with speech and concentration
Jane	Relapses of sodium problem, emergency hospital admission for heart, fall, cataracts removed. 'Going downhill slowly'
Michael	Hospitalised then moved to sheltered housing
Brian	Moved to nursing home by second interview. Died before fourth interview
Rose	Mental health problems linked to bereavement, eyesight and mobility deteriorating, several falls, stroke (3 yrs prior to study) and diabetes.
Margaret	Cataracts. Mental health problems linked to multiple bereavements
Peter	Slowing down, less agile and mobile
Stephen	Decline in mobility, pain in shoulder but cancelled surgery as problems with wounds healing.
Samuel	Stiffness in joints, 'hard to get up every morning'.
Frederick	Mobility very impaired, permanent pain, cataracts
Doreen	Non-diagnosed problem with bleeding from bowel, weight loss, weakening, poor mobility.
Robert	Stomach cancer already spread. Refused chemotherapy and died before fourth interview
Daniel	Falls, diagnosis of low blood pressure. Kidney failure as result of medication
Norman	Worsening arthritic pain in knee but emphysema preventing surgery.
Harry	Heart failure. On oxygen for 18 months. Died before fourth interview
Howard	Slowing down, more painful feet, macular degeneration
May	Deterioration in walking ability, increased pain. Low in spirits.
Phillip	Died shortly after his wife moved to residential care, before third interview.
Ruth	Knee replacement, back on her feet and reasonably stable
Dorothy	Deteriorating mobility. Steroids for lichen planus, psoriasis. Left her partner and moved to sheltered housing
Valerie	Pacemaker fitted, surgery for gallstones, breathlessness. Hospitalised

	3 months (mental health problems)
Elizabeth	Continuing heart problems and poor mobility. Unable to go out independently. Great anxiety about her son's mental health
Irene	Mobility deteriorated. Infection following fall. Now unable to go out independently.